THE INTEGRATION

OF INTELLECTUALLY HANDICAPPED PERSONS

A human and social imperative

ORIENTATIONS AND GUIDELINES

Québec

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90-01143/

Registration of copyright
Bibliothèque nationale du Québec
1st quarter 1989
ISBN 2-550-19326-1

Preamble

The integration of persons having an intellectual handicap is a human and social imperative. This goal inspired the principal directions I announced two years ago. Today, and in the future, it will remain a key objective of the Ministère de la Santé et des Services sociaux.

It was at the request of the intellectually handicapped and their families that the Department was invited to actively recognize their right to enjoy the same quality of life and the same privileges as those enjoyed by the majority.

As Minister of Health and Social Services I, therefore, take great pleasure in presenting this guide for action on behalf of the intellectually handicapped.

This document is the result of much consultation and collaborative effort. It presents the projects which my Department intends to carry out with the help of its various partners. It also identifies certain responsibilities and actions incumbent upon all of us, whether we are ordinary citizens or civil servants.

Our purpose is to consider the individual, not simply as a beneficiary of services, but above all, as a person responsible for his own destiny, and this, notwithstanding his need to call upon the help of others in specific circumstances.

It is important to recognize that social integration is a collective responsibility with which the Ministère de la Santé et des Services sociaux must be closely associated, without seeking to substitute itself for other services nor discouraging local initiatives. However, the close cooperation of all of participants is essential to assure the complementarity and the quality of services received by handicapped persons and their families.

I, therefore, invite all my fellow citizens to mobilize their energies so that together we can offer intellectually handicapped persons the services they require in an environment favourable to the full development of their potential.

The Minister,

Thérèse Lavoie-Roux

Table of contents

Introduction

Part 1: Evolution and present state of services available to the intellectually handicapped

Identification of the intellectually handicapped person 9
Needs of the person and the family 10
Evolution of the services available to the intellectually handicapped person 10

Part 2: The basis of our collective effort

Respect of human rights 13
Guiding principles 14
- Presumption of competency 14
- Promotion of self-reliance 14
- Involvement of the handicapped and their parents or representative 14
- Promotion of parental responsibility 14
- Role of the community 14
- Role of the government 14

Advocated orientations 14
Enhancement of social roles 14
Social integration 15
General objectives 15

Part 3: Services necessary for the social integration of the intellectually handicapped

Services for the community as a whole 17
Services for handicapped people and their families 18
- Support services for the family, milieu and general community services 18
- Services for stimulation, development and support of the handicapped individual 19
- Services for preparation, integration and maintenance in the work force 19
- Residential services 19

Support necessary for obtaining services 20
- Program plan 20
- Individualized service plan 21
- Person in charge of the service plan 21
- Service plan coordinator 21

Legal measures for protection and defense of rights 22

Part 4: Regional organization of services

Guidelines for the organization of services 23
- Priority for services promoting the maintenance or return of handicapped people to the community 23
- Predominance of services geared to personal development and self-reliance 23
- Permanent services for handicapped persons under social protection 23
- Respect for integration potential 23
- Variety and diversity in living environments 23

Essential administrative factors in the regional organization of specialized services for handicapped people and their families 24
- Breakdown into service subregions 24

Structured evaluation system of the needs of handicapped people and their families ... 24
Definition of the roles and responsibilities of each organization in the health and social services network ... 24
Regional structures for inter-network consultation ... 25
Structures for the evaluation of the quality of service delivery and network effectiveness ... 25
Access to services ... 25
Information service ... 25
Mechanism for access to services ... 25
Regional plan for the organization of services ... 26

Part 5: From institutional services to a network of community-based services
Readjusting the roles and responsibilities of the organizations ... 27
Planning the transformation process in the reception centre ... 28
Organizational context ... 28
Rules to be followed in the process of social integration ... 29
Administrative factors to consider when planning the transformation process ... 29
Approval of the project ... 30
Implementation of the transformation plan ... 30

Part 6: Social integration: a collective responsibility
Day care centres and child care services ... 33
Educational services ... 33
Access to the workforce ... 34
Municipal services ... 35
Office des Personnes Handicapées du Québec ... 35
Clients and their parents ... 35
Parent and client groups and associations ... 36

Part 7: Proposals for action
Put a gradual end to the institutionalization of people solely on the basis of an intellectual handicap ... 37
Provide a comprehensive range of specialized services for intellectually handicapped people and their families in each region and subregion over the next five years ... 38
Promote access to services generally available to the population at large by intellectually handicapped people ... 39
Improve the quality of service offered to intellectually handicapped people and their families ... 39
Promote the involvement and participation of parents ... 40
Increase community participation in helping to socially integrate intellectually handicapped people ... 40

Conclusion ... **41**

Bibliography ... **43**

Introduction

For the last fifteen years, the province of Quebec has put considerable effort into helping intellectually handicapped persons improve their living conditions within our society.

The legislative amendments and budget decisions that have characterized this effort reflect the evolution of Quebec society with regard to the needs of its intellectually handicapped population.

In June 1986, the Minister of Health and Social Services reiterated the Department's intention to increasingly promote the social integration and reintegration of the intellectually handicapped. In light of its commitment to assume greater leadership in this area, the Department conducted consulting sessions and various work groups for the purpose of elaborating a series of guidelines to be used as a framework for the integration and reintegration of handicapped people and the reorganization of all affected resources. In this way, the Ministry expects to allay the concerns and apprehension of various groups which, while recognizing the advantages of community integration, question the strategies or means to be employed in this process. Their main concerns are in the area of accessibility and quality of the services available in the community to the intellectually handicapped, and the possible impact of such a project upon the community.

According to the consultations of the last few years, there seems to have emerged a general concensus regarding the overall objectives of this process and the right of the intellectually handicapped person to an active and participative role in the community.

It is also generally acknowledged that many intellectually handicapped people require assistance in order to develop and assume an active role in community life, as well as social, protective measures in order to deter abuse or increased isolation. The Government plays a major role in this area. It must ensure that the protective measures required by these people are in place and that their community participation is sufficient to promote social integration.

The Ministère de la Santé et des services sociaux must ensure that "change" respects its ministerial orientations and improves the living conditions of intellectually handicapped persons and the quality of services available to them.

This document identifies some services needed to prevent institutionalization and to support the process of community reintegration. It also touches various aspects of the regional planning process and the reorganization of institutional services and resources leading to the creation of community-based services.

Since the social integration of handicapped people depends on the collaboration of everyone and will require much more work in the years to come, the last two parts of this document outline the collaboration expected from other providers of public and private services, as well as the various objectives the Ministère de la Santé et des Services sociaux expects to see implemented in the future.

Finally, in an effort to put everything into perspective, the first chapters, based on the June 1986 declaration and on other departmental documents, describe the services in their present state with regard to the intellectually handicapped and the principles and orientations promoted by the Department.

PART

1

Evolution and present state of services available to the intellectually handicapped

Over the years, our conception of mental retardation has greatly evolved. The many names that have been used to designate the intellectually handicapped bear witness to the evolution of these various conceptions and, consequently, of our attitudes toward the individuals themselves, their needs, and the services made available to them.

The medical field was the first to lay down classifications. The evaluation of mental retardation was based on physical appearance, causes or effects, and service delivery centered either on the causes of the handicap or on the associated handicaps to be treated or cured. Mental retardation was then often identified as a mental illness or an emotional disorder.

The social sciences and humanities have evolved to the point where mental retardation is now perceived as a learning disability and related to an insufficient level of development of adaptive capacities.

The work of the World Health Organization fits in with this perspective. The introduction of such notions as deficiency, incapacity and handicap enable mental retardation to be seen as a learning disability resulting in delayed skill development, thereby hindering the individual's ability to fulfill the demands of his environment unless appropriate specific measures are taken.[17]

The community is thus responsible for immplementing measures aimed at adapting its activities to the needs of the intellecually handicapped. The efforts of the community and its institutions should help the intellectually handicapped to develop their skills and support them in the exercise of their autonomy.

Identification of the intellectually handicapped person

A wide range of definitions exist in the area of mental retardation. Only the following definition of the American Association on Mental Deficiency seems to be universally accepted:

"Mental retardation refers to significantly subaverage general intellectual functioning, existing concurrently with deficits in adaptive behaviour and manifested during the developmental period."[13]

According to certain studies there are an estimated 200,000 intellectually handicapped people living in Quebec. Of these, 88%, or 2.64% of the general population (176,000 individuals), have a mild handicap and 12%, or .36% of the general population (24,000 individuals), have a severe handicap (moderate, severe, very severe).

Special services are not required in all cases of mental retardation. According to the Canadian Association for Community Integration, close to one out of every three cases of mental retardation, or 1% of the general population, requires specific services on a regular, lifetime basis.[7]

For its part, the Swedish Government affirms that close to 0,45% of its population is intellectually handicapped to the extent that such persons require particular attention and specific regular services.[19]

Research carried out in the northeastern United States estimates that 500 to 700 persons out of a population of 100,000, that is 0.6% of the general population[15], are in need of specialized services.

Specialized services in Quebec must therefore be able to meet the needs of an estimated 40,000 people.

Needs of the person and the family

Intellectually handicapped people have the same basic needs as everyone else. Without appropriate assistance, however, they may sometimes experience difficulty in accomplishing, on their own, everything required of a self-reliant person. They will therefore need specialized services to fulfill their basic needs and fully exercise their rights.

The nature and severity of these specific needs can vary during the different stages of life. Once a handicap has been detected or identified in the newborn, it is mainly the parents who need support and ask for assistance in the area of self-education as to the nature and extent of the problems of their child. Specific needs will be preventive in nature or rely on the correction of functional, congenital anomalies.

After the stimulation of the first few months come more specific training programs to be carried out with the child, then integration into day care and other services available to the general public. Parents will also need guidance and support during this period, and resource people can be invaluable in giving appropriate support and assistance in the training process.

Needs change when the child is old enough to go to school. It is then a question of integration into the neighbourhood school and of making available services adapted to his specific needs and developmental capacities. It is also important that leisure activities be adapted to the aspirations and tastes of the individual in the context of social integration.

Even when integration has been accomplished at school and at the recreational level, the individual and his family may need support and educational assistance in order to overcome a learning disability or any other problem. The family may also need a substitute residential resource capable of lending a helping hand or of taking over if a break is needed. Such times, if well organized, can be a positive experience for the individual and family.

Adulthood means new responsibilities and roles for the handicapped individual. The family becomes less prominent in his life, and society, through its various support organizations, must gradually take over and meet the needs of the individual, who will want to be trained and integrated into the workforce and live in a separate residential environment. The individual may also need additional support and assistance in order to effectively carry out his new role.

Likewise, in relation to special needs related to aging, the individual will have to have access to all services available to the elderly, including, if necessary, the services related to his initial handicap.

Evolution of the services available to the intellectually handicapped person

It was really only at the beginning of the 19th century that most of the western world started to recognize the special needs of handicapped people and of the necessity to help them. Until then, they were left to themselves or were dependent upon their families.

Around the second half of the 19th century, the first public services for the intellectually handicapped became available in Quebec. For a good many of these people, these services meant that they were taken from their home environment and placed in an institution. This approach prevailed until the nineteen seventies, at which time more than 10,000 people were placed in various institutions.

Around the nineteen fifties and sixties, people began to realize that this approach was not producing the expected results, and that it caused major problems for the residents themselves.

Institutional placement no longer constituted a respectable environment in accordance with the rights of the residents.

Research having shown the advantages of the home environment and the negative consequences of institutionalization, ideological movements, mainly the one for normalization and enhancement of the social role, as well as the activities of advocacy groups, all led to the emergence of the social integration movement.

These factors put pressure on the network of institutional services to improve the quality of their services and, more importantly, to reintegrate intellectually handicapped people into the community. This movement toward integration also had major consequences for private and public services geared to the general population. Service delivery had to adapt to deal with handicapped people.

However, despite the importance of the social integration movement and the efforts of many groups in this area, the number of people residing permanently in institutions run by the Ministère de la Santé et des Services sociaux remains high. Moreover, those living out in the community have little access to services and facilities available to the general public or to support services and rehabilitation services. External support services have been made available mainly through the reorganization of reception centre resources. However, these services are still clearly inadequate for avoiding institutionalization or enabling social and physical reintegration of those already institutionalized.

All service networks must strive to better serve handicapped people and to ensure quality living conditions for these people within the community.

PART
2

The basis of our collective effort

Until now, the Quebec Government, and more specifically the Ministère de la Santé et des Services sociaux, has not come out with a specific policy or specific legislation regarding the intellectually handicapped. The special needs of these people have generally been included in policy and legislation regarding services and programs developed for the handicapped in general or for the general population.

The main documents on orientation and policy include *Mémoire de programmes: les services à l'enfance*, published in 1973, the white paper *Proposition de politique à l'égard des personnes handicapées*, which preceeded the adoption of a Bill to promote the rights of handicapped persons, and lastly, *Les orientations du ministère de la Santé et des Services sociaux en regard de l'intégration et la réintégration des personnes présentant une déficience intellectuelle*, published in June 1986.

These documents, as a whole, outline the orientations, principles and general objectives meant to guide those involved in the planning and organization of services available to the intellectually handicapped. These documents acknowledge the respect of human rights as their basic foundation.

Respect of human rights

The main legal texts forming the basis of human rights are:

- the Declaration of Human Rights (UN, 1948);
- the Declaration of Children's Rights (UN, 1959);
- the Declaration of Rights of the Mentally Deficient (UN, 1971);
- An Act Respecting Health and Social Services (R.S.Q., c. S5);
- the Charter of Human Rights and Freedoms (R.S.Q., c. C12);
- the Declaration of Rights of the Handicapped (UN, 1975);
- An Act to Secure the Handicapped in the Exercise of Their Rights (R.S.Q., c. E-20.1);
- the Youth Protection Act (R.S.Q., c. D-34.1);
- the Canadian Charter of Human Rights and Freedoms (1982);
- the Civil Codes.

The above mentioned charters and acts acknowledge all human beings as equal in rights and dignity, and the handicapped as having the same rights as all other members of the community. The handicapped have the right to life, to freedom and to the integrity of their person. They are full citizens and have the right to be heard and the right to appeal all decisions pertaining to them.

Moreover, this principle refers to the following set of rights:

- the right to the same protection and to the same benefits under the Law;
- the right to economic and social security;
- the right to measures enabling them to achieve maximum self-reliance, to grow and to develop throughout life.

Leglisation on health and social services acknowledges the right to these services and specifies that the organization and distribution of the services must be permanent, individualized and in accordance with recognized scientific, human and social criteria.

Consequently, the organization of services to the intellectually handicapped must recognize the primacy of their rights and interests.

Guiding principles

In accordance with the values and principles stated in the above mentioned documents, the conceptual framework contains certain guiding principles:

Presumption of competency

This principle assumes the potential of the individual for development and acknowledges the fundamental right to maintain and develop one's skills. Each person has the opportunity to meet challenges and to take advantage of means promoting personal development in all activities of daily life.

Promotion of self-reliance

This principle involves giving the individual the means and appropriate support for making choices and being responsible for his personal, social and economic life, leading to a useful and productive life, thereby contributing to the well-being of the community.

Involvement of the handicapped and their parents or representative

The parents of an intellectually handicapped child, or the person legally responsible for him, are the most directly concerned by the plans for the life of their child. They must take an active part in the decisions affecting their child and his future. As an adult, the individual, with his representative as the case may be, must be involved in the planning of his own future, and must be able to adapt the basic orientations of his life.

Promotion of parental responsibility

Parental responsibility and obligations toward a handicapped child are identical to those of any parent. Indeed, parents must satisfy the basic needs of affection, security and development of their child. The role of the government is to support parents in this regard. Parental responsibility changes when the individual comes of age. If the individual is not autonomous, the government must ensure the assistance necessary for his well-being and protection.

Role of the community

The community has the potential to support the individual during the process of social integration and contribute to his overall well-being. The community is crucial to the development of the quality of life of the individual.

Role of the government

The government must assume the additional costs related to the handicap incurred by the individual and the family in the fulfillment of the basic needs of the individual. It must become a leader in the development and integration of the intellectually handicapped and overcome the difficulties that affect their well-being and safety. The government must also adapt its services to make them accessible and available to all handicapped people.

Advocated orientations

Enhancement of social roles

Enhancement of the social role of the handicapped must constitute the basic orientation of our policies and actions. This prerogative is a refining of the principle of normalization as it exists in the white paper entitled *Proposition de politique à l'égard des personnes handicapées*.

This orientation has two basic aspects:

- development of personal capacities and skills;
- improvement of the individual's social image.

Development of personal capacities and skills presupposes an assumption of competency and the adoption of program plans oriented toward personal growth. It also requires the use of appropriate learning techniques and technology.

Improvement of the social image of the individual requires appropriate social roles corresponding to the age and sex of the individual, and to the culture of the community. It also supposes the existence of a support system necessary for improving their image through the fulfillment of their specific needs.[21]

Social integration

Social integration is a corollary of the enhancement of social roles.

Successful social integration means that the handicapped person has activities, opportunities, privileges, etc. similar to those existing for and expected by the nonhandicapped person.

Social integration includes:

- *a physical dimension* which consists of sharing the same living space as any other person;
- *a functional dimension* which enables the individual to use community services, facilities and equipment available to everyone under the same rules;
- *a community dimension* which enables the person to benefit from meaningful relationships with other people, to have privileged affective relationships, to enjoy privacy and to have status within the community.

General objectives

Our goal as a community must be to provide the opportunity for the intellectually handicapped person to sustain a high quality of life. This goal will be achieved when social integration has become a reality for everyone and the social image of handicapped people has been improved.

The Ministère de la Santé et des Services sociaux will collaborate in the realization of this collective challenge working to achieve the following objectives:

- keep the child in the home and the adult in a residential environment of his choice;
- develop the individual's self-reliance in his normal environment;
- encourage the individual to participate in community life;
- develop vocational competence in the adult and encourage his integration into the work force;
- encourage social contact between handicapped and nonhandicapped people;
- support this individual in the exercise and defense of his rights;
- reintegrate individuals currently institutionalized back into society.

PART
3

Services necessary for the social integration of the intellectually handicapped

Departmental efforts in the area of social integration are oriented toward promoting access to general services, providing specialized services tailored to the specific needs of handicapped people, and integrating them into the community. These efforts also involve a wide range of services and programs that often transcend the needs directly related to the individuals themselves. The families of the handicapped, as well as various community organizations and public services, may also have special needs.

These services must fit into a global approach that respects the needs of both the individual and his milieu. This new outlook thus requires the creation of a new service network with the following characteristics:

- **the utilization and adaptation of general services** to the specific needs of the intellectually handicapped;
- **the availability of a range of specific services** focusing on the development and support of the handicapped and their families;
- **a support system necessary for obtaining services;**
- **legal protection measures.**

As a whole, these services strive to fulfill the basic needs of handicapped people and their families. These services represent an intermediary between the handicapped individual and his milieu, and are designed to improve the individual's ability to fulfill his own needs and to adapt to his own milieu (society, services, etc.), in order to shrink the gap between the individual's abilities and the degree of self-reliance required in order to live in the community. If these orientations are to be followed, the measures employed must be socially acceptable and socially enhancing to the handicapped individual.

Services for the community as a whole

Integration of the handicapped individual is impossible without the acceptance and support of the community and without access to general community services. The community must adopt a positive attitude and its general services must be accessible to handicapped people in order to fulfill their basic needs.

The Ministère de la Santé et des Services sociaux has always favoured an integrated approach to implementing its orientations, thereby preventing a single institution from providing all services usually offered by a range of other institutions, governmental departments or agencies. A great number of general services available to everyone require no specific adaptation to accommodate handicapped people except for, perhaps, a specific client-professional approach.

However, other agencies require specific adaptations in order to be available for and accessible to handicapped people. Some of these are:

- infant stimulation programs in the family environment and in local day care centres;
- support systems in regular classes or in neighbourhood schools;
- municipal and private recreational services;
- adapted transportation services;

- vocational training programs and programs for the adaptation of the workplace;
- special family allowance program;
- adapted social assistance programs.

To find solutions that facilitate adaptation of their services, the departments and agencies responsible for these programs could benefit from the network's support. Such collaboration will be all the more efficacious if the community and all individuals are made aware of the problem and come to recognize their responsibility regarding the social integration of intellectually handicapped persons.

Services for handicapped people and their families

These specialized services are aimed mainly at developing self-reliance in the handicapped person and supporting him in the integration process. They also strive to assist the families and the people providing the general services to the handicapped. A good many of these services are considered to be adaptive or rehabilitative services, most of which must be provided on an individualized basis.

The following lists, although not quite complete, constitute nonetheless a wide range of services; more over, the following should be provided in each region:

- support services for the family, the milieu and general community services;
- services for the stimulation, development and support of the handicapped individual;
- services for the preparation, integration and maintenance in the work force;
- services in a residential environment.

Since these services vary in importance, they must be set up in an order based on the needs of the handicapped and of his environment.

Support services for the family, the milieu and general community services

Support services for the family, the milieu and services in general respond to a series of problems.

The family environment, preferably the natural family, is the most appropriate environment for the emotional growth and personal development of the child.

Consequently, in order to encourage the maintenance of the child in his home environment and enable parents to adequately assume their roles and responsibilities, they must be given access to a series of assistance programs and support services.

In the same way, certain community organizations, such as day care centres, schools, and recreation centres, need information and assistance to adapt their services to the intellectually handicapped.

The following list of support services is given as a guide and is not exhaustive:[12]

a) detection at birth and in the early years;
b) psychosocial support for the individual and family;
c) information about retardation, its causes, the capacities of the handicapped individual, the services available and access to them;
d) growth, support and mutual aid groups for the parents (support parents) and siblings;
e) respite and home care services;
f) special respite service for the handicapped individual in the event of emergency in the family (death, hospitalization, etc.);
g) educational assistance to the family, local day care centre and school;
h) special measures for the purchase of specific goods and services such as home adaptation devices;
i) family housekeeping service.

Services for stimulation, development and support of the handicapped individual

Every individual, regardless of the nature and degree of his handicap, has a right to personal growth and development.

Each service provider must therefore promote an approach leading to the individual's self-reliance and his participation in the life of the community.

Services for the stimulation and development of children must take precedence and be available to all.

The principal services and programs are the following:

a) infant stimulation;
b) support services in local day care facilities;
c) support programs in the formal education of children;
d) training services for residential life, integration into the community, and utilization of general community services;
e) specialized programs in learning adaptive social behaviour;
f) services for the acquisition and development of language (oral or other);
g) home services in personal hygiene, meal preparation, shopping, housework, etc.;
h) counselling services in budget management for adults;
i) support services for integration into recreational services (municipal, holiday-oriented and other);
j) support services for general integration into the community.

Services for preparation, integration and maintenance in the work force

Despite the importance of integration into the work force, services in this area are relatively recent and not particularly developed.

The long accepted approach, developed essentially in protected workshop surroundings, does not represent the only training strategy for intellectually handicapped people. On-site training programs (preparation for the work force and on-the-job training) could be developed and adapted to the capacities of the handicapped people using opportunities available within the work community.

Essentially, these services are designed to prepare the handicapped individual to enter the work force or to take on a productive work situation in accordance with his own aspirations. These services include:

a) evaluation of work capacities;
b) acquisition of skills and work habits necessary to obtaining a job;
c) on the job training;
d) location of work stations and individual on-the-job training sites on a part-time or full-time basis;
e) on-the-job counselling and follow-up;
f) vocational training.

Residential services

The physical integration of the handicapped person into a residential environment is an essential part of the social integration process. Residential services include support programs to enable handicapped people to live with their family or in an apartment situation, or to offer them a residential environment in the community. In the case of a child, this substitute environment replaces the family; in the case of an adult, it takes the place of an individual's independent living situation.

Support services at the residential level must be adapted to the degree of autonomy and development of the handicapped individual. Many people in an integrated environment need these services on a regular basis. When a handicapped person in need of state sponsored social protection has to change residential environments, it is imperative that the organization in charge ensure the continuation of services until another organization, better equipped to fulfill his needs, assumes responsibility for the person.

With the exception of the group home, where the ideal number of occupants is four, the other residential services for adults should not accept more that two or three persons under the same roof. In the case of the intellectually handicapped child, the ideal residential service would accept only one child at a time.

RESIDENTIAL SERVICES FOR CHILDREN

The intellectually handicapped child does not usually need a substitute residential service.

Generally, the child must have access to services developed for children in general. As in the case of countless other children, if for whatever reason the parents of an intellectually handicapped child cannot assume their parental duties, the child shall be placed in a regular, special or readaptive foster home. In all cases of parental abandonment or neglect, steps shall be taken toward adoption.

However, it is possible that a very small number of children may need a substitute residential service on a temporary basis. For this reason, it seems necessary to maintain group homes for children with severe or multiple handicaps or behavioural problems that put them or those around them at risk, and who necessitate intensive and specialized programming on a temporary basis.

RESIDENTIAL SERVICES FOR ADULTS

As intellectually handicapped people mature, the family's role becomes less prominent. The intellectually handicapped adult, just like any other adult, looks for a residential environment distinct from his original family situation. Society must therefore gradually replace the natural or foster family with the appropriate support services.

With regard to social and community integration, the handicapped person needs, above all, support and assistance in his living environment.

Service providers must ensure at all times the welfare and security of the intellectually handicapped person. To that end, they must propose the environment best adapted to the needs of the person, as well as the appropriate levels of assistance and supervision. The scope of these services has to be adjusted to the level of development of the handicapped person.

Living arrangements are the same for handicapped people as they are for everyone else, namely apartment, single family unit, boarding house, etc.

These arrangements allow handicapped people to live as independently as possible with a minimum of constraints. Handicapped people must be able to develop relationships and have a right to privacy in their place of residence.

As in the case of children, substitute residential services such as the group home must be considered as a last resort and only on a temporary basis.

Support necessary for obtaining services

The handicapped individual must have access to complementary and continuous services to develop self-reliance and to allow the person to remain in his natural surroundings.

The needs of the handicapped cannot be adequately fulfilled without access to individualized or tailor-made services.

Program plan

According to regulations for the administration of organizations covered by our Laws respecting health and social services, a program plan must include the following: identification of the needs of the client, objectives to be attained, methods used to meet these objectives, and a time line for these services.

Each plan is, in fact, a strategy aimed at attaining objectives of personal development, social integration and participation in the life of the community.

All organizations must draw up a program plan for each of their clients and revise it every 90 days.

Individualized service plan

For most handicapped people, appropriate social integration requires an individualized service plan. This plan is a tool that ensures planned and coordinated resource and service delivery capable of fulfilling the needs of the individual by promoting autonomy and integration into the community.[3] The plan also ensures that programming is coherent and complementary, and based on the needs of the client.

The individualized service plan has several elements:

PLANNING:

clarification of the services, programs and activities necessary for the individual and his family or living environment on a mid-and long-term basis;

COORDINATION:

provision of the resources and the services required to meet objectives determined on the basis of the needs of each individual. Coordination requires the collaboration of all concerned;

PRESERVATION OF RIGHTS:

on the one hand, inclusion of the elements required to defend and promote the rights and interests of handicapped people and, on the other hand, the preservation of those elements which promote the highest quality of service.

The individualized service plan guarantees access to the various services required by handicapped people, while enabling better coordination of the differents forms of intervention.

However, this plan is not essential for all handicapped people, and not necessarily required on a permaneht basis. In many cases, the needs of individuals may be fulfilled by a single referral with follow-up.

Person in charge of the service plan

The handicapped adult, or his legal representative, or his parents in the case of a handicapped child, assumes responsibility for the implementation of his service plan.

Since this plan is centered on the needs of the handicapped individual, it is essential that he take an active part in its preparation. At the meeting set aside for the service plan, the handicapped child may accompany his parents or his legal guardian. As for the handicapped adult, he will be accompanied by his legal representative, as the case may be. The adult may also invite his parents or any other person of his choice. The individual and his representatives have the right and the obligation to participate fully, to appeal decisions, or even to refuse a service. If either the handicapped individual or the person responsible for him is dissatisfied with the services offered, the Office des personnes handicapées du Québec may be called upon to represent the interest of the handicapped individual and to assist in putting forward his demands.

Service plan coordinator

Upon request, the service plan coordinator acts as a representative of the handicapped individual, his family or his legal representative in the implementation and revision of the service plan. In addition, the coordinator assists the handicapped individual in

defending and maintaining his interests and rights, and ensures a degree of coherence between the organizations dispensing services. It is therefore preferable that the coordinator provide no direct service to the handicapped individual, in order to avoid confusion and conflict of roles.

Legal measures for protection and defense of rights

The handicapped person has the same basic rights and privileges as any other citizen. The family has the same rights and responsibilities toward their handicapped children as they have toward their non-handicapped children.

Certain legislative weaknesses are often invoked regarding protective measures for the individual and his possessions, procedures for internment or access to care. The current legal protective measures were established in a context where the handicapped were hidden away from society. These measures must be adapted to promote support of the handicapped in the community.

Much needed new measures would enable handicapped people to exercise their rights and responsibilities with support in matters beyond their level of decisional competence. These measures would apply to management of their possessions, to support required in the exercise of their independence, and to the appeal process in the course of obtaining appropriate services.

PART

4

Regional organization of services

In order to ensure that intellectually handicapped people receive appropriate services, it is essential to draw up a regional organizational service plan. To implement services on the local and regional levels, the regional councils will have to determine the organization of services, taking into consideration certain parameters found in this document and local characteristics of their regions.

With this plan in mind, each regional council will have to evaluate the needs of handicapped people in its region and draw up a current inventory of services. In so doing, the council will be able to identify the nature of the services required and the resources to be allocated or reallocated, as the case may be.

The organization of services will be oriented toward the needs of handicapped people within the context of regional priorities, and will give these people access to a complete range of community-based services.

Guidelines for the organization of services

Certain factors must guide the organization and development of a service system for intellectually handicapped persons and their families. These factors apply both to general and specialized services.

Priority for services promoting the maintenance or return of handicapped people to the community

With social integration as our goal, the main services to be developed are ones which promote the social participation of handicapped people in the life of the community and the return of institutionalized people to their natural milieu.

Predominance of services geared to personal development and self-reliance

These services must meet the developmental needs of handicapped people throughout their lives so that they may live in their own home milieu. Such services will enable them to get the most out of life and reach their maximum potential. The development of these services must take precedence over other services.

Permanent services for handicapped persons under social protection

Intellectually handicapped people under social protection must be able to depend on the permanence and reliability of their services. The regional service plan must ensure that services earmarked for the handicapped be in place and adequate to meet their needs.

Respect for integration potential

When the proportion of handicapped people living in a given area is too high, their successful physical and social integration are put at risk.

Any project involving the social reintegration of handicapped people through the establishment of community-based services in an integrated milieu must respect the relative number of the target population in relation to the global population.

Variety and diversity in living environments

Community involvement of handicapped people in activities at the residential, school, recreational or work levels must reflect the habits of the majority of the population.

This implies, in particular, that the use of facilities and participation in activities be as normalized as possible.

Essential administrative factors in the regional organization of specialized services for handicapped people and their families

The nature and variety of the needs of handicapped people require the organization of a complex service system. It is also understandable that this system must reflect different local and regional particularities or "colour".

However, structures must exist in all regions:

- to prevent conditions which might lead to an increase in the prevalence of a learning disability or an intellectual handicap;
- to identify those people who have or who could have an intellectual handicap;
- to provide infant stimulation services in order to reduce the impact of the handicapping condition;
- to improve and develop the skills and abilities of handicapped people;
- to reduce the social isolation of handicapped people and promote their integration into the community.

The organization of services must also include a certain number of common elements considered to be essential in order to ensure adequate service quality, social equality and minimal service duplication.

Breakdown into service subregions

The size, geographical particularities and population basins vary from region to region. Handicapped people naturally look to specific areas for the services they need. In order to ensure availability, access, complementarity and complete coordination of services for handicapped people and their families as near to their place of residence as possible, the subdivision of a region into service subregions is favoured.

Regional councils, together with their partners, will have to choose the territorial breakdown best suited to the needs of handicapped people and the region. In addition, they will have to ensure some degree of social equality at the subregional level, while respecting their demographic, cultural and economic realities.

Structured evaluation system of the needs of handicapped people and their families

A structured system of evaluation will facilitate communication between all parties and open the way for a common outlook on the needs and services required. Knowing these needs is also necessary for planning the evolution of specific services. It is therefore advantageous for each region to use a common system to evaluate the needs of handicapped people and their families.

Definition of the roles and responsibilities of each organization in the health and social services network

The roles of organizations in the network are defined in the Act respecting health and social services, together with its regulations. The evolution of services should therefore occur in accordance with the mandate of each organization. However, since service providers are diverse and unevenly distributed across Quebec, each regional council, together with the organizations of its region, must clearly identify the responsibilities of each partner organization.

Regional structures for inter-network consultation

The coordination of services to handicapped people and their families means pooling diverse resources in order to adequately fulfill their needs, including those for which the health and social services network is not directly responsible. The collaboration, complementarity and cohesion of the various agencies and organizations, private and public, remain essential.

Each regional council, in collaboration with the Office des personnes handicapées du Québec, must develop a mechanism for regional coordination in order to regroup the administrators and professionals connected with the various organizations and government departments. This will facilitate the consultation required to ensure the availability of services and more easily identify needs as a whole with regard to the evolution of services.

Structures for the evaluation of the quality of service delivery and network effectiveness

Each region must set up an evaluation system reflecting the conformity of services with the main orientation as defined by the Ministère de la Santé et des Services sociaux, as well as the appropriateness of the services provided with respect to the needs of the clients. The effectiveness and efficiency of the service network, by subregion, may be evaluated at the same time.

Access to services

Intellectually handicapped people and their families must have easy and rapid access to services corresponding to their needs Thus, in each region, the appropriate "front door" to the service system must be identified and a mechanism of access to social services must be put into place.

Information service

Each regional council must set up an information service to keep the population aware of the services available to handicapped people.

This could take the form of a telephone service or a specific office designated by the regional council. Interested persons will thus be able to inquire about where they must go to receive a specific type of service.

However, the mentally handicapped individual, his representative and his family may also contact public service organizations directly (CAR, CLSC, CSS, CH etc.) for the required services. Reorientation will be done by each of these organizations in the event that they cannot provide the required services.

Mechanism for access to services

Each region must set up a mechanism to facilitate access to services provided by the network and to promote collaboration between the various regional partners. It is the responsibility of the regional council to set up such a mechanism.

Two central aspects characterize the mechanism of access to services:

- evaluation of needs and creation of a service plan;
- identification of service providers in order to implement the service plan.

To accomplish the above, two committees will be put into place:

COMMITTEE FOR THE EVALUATION AND ELABORATION OF THE SERVICE PLAN:

Consisting of the interested parties from the service network designated by the regional council, this multidisciplinary team will gather the necessary information, meet the handicapped individual, his legal representative or his family, and draw up with them a service plan adapted to the specific needs of the client. This plan shall later be forwarded to the committee for the identification of service providers;

COMMITTEE FOR THE IDENTIFICATION OF SERVICE PROVIDERS:

Formed by the regional council, this committee is composed of directors representing the various organizations in the health and social services network, and other services, as the case may be. For each intellectually handicapped client, this committee designates the organizations responsible for providing the necessary services within a suitable time frame. If necessary, the committee also identifies the organization responsible for designating a service plan coordinator.

Each region must specify the nature of the services for which this mechanism of access will be used. However, use of this mechanism will be compulsory for all persons:

- requiring services offered by the various public service organizations;
- requiring a change in the degree of supervision at the residential level;
- requiring legal protective measures;
- whose service needs cannot be fulfilled due to a lack of resources in the region.

The referral policy regarding the mechanism of access will be determined by those responsible for the organization of services. However, parents may have recourse to it if necessary.

This mechanism also allows for the systematic revision of each service plan on an annual basis in the case of children, and every other year for adults. However, all plans may be revised upon request. The committee for the evaluation and elaboration of the service plan will be responsible for this revision.

Regional plan for the organization of services

In order to ensure the establishment of a complete range of accessible, quality services for intellectually handicapped people, each regional council, together with the parties involved, must draw up a plan for the organization of services on a regional level. Through such a plan, all parties involved (promotion agencies, rehabilitation centers, social service centers, local community service centers, hospital centers dispensing services to intellectually handicapped persons, etc.) will share a common understanding of the services offered in the region and of the mandates and expectations of the various service partners.

In addition, this plan will represent a basis for subregional, regional and interregional consultation among all public organizations concerned. The plan will also serve as a guide for the development or reorganization of services, or for the allocation and reallocation of resources in the region. It shall also be a guide for the continuous evaluation of the services themselves.

The plan for the regional organization of services will respect the evolutionary nature of the needs of handicapped people living in a specific region, ministerial orientations and priorities, available resources and, lastly, the contribution of the community. It will include:

- identification of the needs of the intellectually handicapped;
- nature of available services;
- principal mandates handed down to the various public service organizations;
- identification of adjustments or reorganization needed in the services or the resources which they will require;
- procedures for access to services;
- regional structures for intra- and inter-network consultation;
- systems for evaluation of service quality;
- etc.

In addition, this plan will indicate the proposed development of services for the region on a triennial basis and will be forwarded to the Department for study and approval.

In short, the plan for the regional organization of services will contribute to a better balance between the needs of handicapped people and the services available in each part of the region.

PART
5

From institutional services to a network of community-based services

Despite various experiments in social reintegration and numerous attempts to develop services better adapted to the needs of intellectually handicapped people, there are reception centres and psychiatric hospitals where a large number of people are still interned and where a major part of the resources are still allocated to internal services.

Acknowledging the right of intellectually handicapped people to the same quality of life as any other person requires setting up various systems and services. This process would be impossible without the close collaboration of all partners in the health and social services network. Moreover, the social integration and reintegration of intellectually handicapped people will result in a readjustment of the roles and responsibilities of certain public agencies in order to appropriately meet the needs of the clients.

Lastly, due to the fact that the majority of the resources of the reception centre network is currently allocated to institutional services, social integration and reintegration will lead to organizational changes and adjustments for the workers and managers of these institutions.

Readjusting the roles and responsibilities of the organizations

The Castonguay-Nepveu reform greatly influenced the distinction of roles and responsibilities in each category of public service organizations.

Immediately following this reform, each category of organization was given specific roles and responsibilities which, on the whole, have remained relatively unchanged until now.

Thus, during these years, job specialization created various traditions in professional practices. Each service now has well defined tasks and spheres of activity and, usually, a set workplace.

The approach giving precedence to a service network centered on the fulfillment of the needs of handicapped people and their families cannot work if the same roles and responsibilities are maintained, or if new ones, perfectly adapted to each category of organization, are attributed in the same fashion for each region of Quebec.

Regions and institutions with varying degrees of leadership, resources and techniques have already experimented with very often original consultation methods and service models. Uniform redefinition of roles and responsibilities for every institution could compromise the transformation process and would be against the very principle of adaptation of services to intellectually handicapped people. However, although each institution is required to abandon the conventional vision of its roles and responsibilities to better ensure the evolution and adaptation of its services to the needs of handicapped people, the mandate of each agency shall be globally respected nonetheless.

For these reasons, regional health and social service councils have a mandate to clarify, in collaboration with the agencies, the roles and responsibilities of each one, by building on local and regional achievements and by using the expertise already acquired in adaptation and readaptation by the reception centres. The setting up of a service network should not be compromised by the present legislative and regulatory framework

or by respect for the vocation of each institution. The plan for the regional organization of services will require flexibility on the part of everyone involved.

Planning the transformation process in the reception centre

The setting up of a network of services will be done mainly through the conversion and reallocation of the centres' existing services and resources.

The transformation of resources will in fact consist of going from centralized management, where staff is generally grouped in one place, to a decentralized model of management based on personalized services to handicapped people. These changes will affect organizational structures and the distribution of services, as well as the role of all parties involved, and what is required in terms of training and experience.

In this context, planned change, taking into consideration both the needs of handicapped people and the workers, is absolutely essential for centres. The collaboration of their employees and of their network partners is also crucial to this process. The centres must also foresee and build structures that facilitate the transition process while at the same time respecting everyone involved.

Organizational context

It is a fact that the social integration of handicapped persons involves a collection of social agencies and partners, because one of its objectives is the promotion of the use of community services by handicapped people. Each institution must therefore be able to evaluate itself with respect to its clients, services and resources, and to correctly situate itself in relation to its role within the process.

With respect to their own organization, administrators must first:

- identify their clientèle;
- evaluate their needs in terms of services and resources;
- identify the involvement and participation of the client, his parents, or any other person instrumental in the process of social integration
- identify and describe the nature of the programs and services offered by the institution;
- identify the values conveyed by the organization in each of its groups (board of directors, management team, employees directly and indirectly involved, etc.);
- evaluate the participation of the organization's various constituted bodies (union, clinical staff advisory board, beneficiairies' committee, parents' committee, etc.);
- identify and describe all available human, material, and financial resources.

Secondly, administrators must describe their environment and, more specifically, the following aspects of it:

- regional organization of services;
- range of accessible community-based services (general or specialized) capable of fulfilling the needs of intellectually handicapped people;
- network partners and existing structures for consultation;
- evaluation of the receptivity of the community (population, municipality, school boards, etc.) to the social integration of handicapped people;
- socio-economic impact of any reorganization (shutdown of a facility, for example).

Through this exercise, administrators will be able to analyze the organization and its environment, as well as evaluate both the elements likely to facilitate the integration of the handicapped into the community, and the difficulties for which solutions must be found.

The management team will later be able to set specific priorities or objectives to guide them in achieving the social reintegration of their handicapped clientele.

Rules to be followed in the process of social integration

Regardless of the problem of regional disparity, the number of handicapped people to be integrated, and the size of the organization, certain rules remain essentially the same during the transformation of institutional services into community-based services.

Thus, any public organization working toward social reintegration must:

- adequately prepare the person re-entering the community;
- draw up action plans which are based on the needs of the handicapped clients and which ensure adequate follow-up;
- ensure that each handicapped person has an individualized service plan;
- ensure the participation of the adult, his representative, or the family in the case of a child, in the decision-making process by keeping them informed and by constantly supporting them in their actions;
- ensure the involvement of all the constituted bodies of the organization (board of directors, management team, unions, workers, clients' committee, etc.) in the process of change, and ensure that these groups make a commitment to the intellectually handicapped person and are motivated to facilitate his integration into the community;
- ensure that a network of diversified services based on the needs of the handicapped is present and available in the community;
- maintain permanent basic services (shelter, food, supervision) to non self-reliant individuals in need of social protection, and ensure follow-up;
- respect the provisions of the collective agreement;
- plan programs for updating the expertise of the workers in order to involve them more in the process of social integration and reintegration, and to ensure its success;
- in collaboration with regional councils, prepare the community, mainly community groups, through the use of sensitization and information activities, in order to increase the receptivity of the milieu and change negative attitudes toward intellectually handicapped people;
- set up evaluation systems enabling the organization to measure the quality of life of intellectually handicapped people in the community and to make the appropriate adjustments where necessary.

Administrative factors to consider when planning the transformation process

This complex process of institutional transformation requires a high degree of conviction on the part of the administrative team. Indeed, depending upon the organization in question, the transformation of services and resources results in a change in the organizational structure and in management policies at both the professional and administrative levels.

The principal matters to be considered when planning such a change are listed below:

— reorganization of services:

- identification of new external resources;
- organizational structure of external services (new organization chart);
- administration of services (quality control, supervision of staff, etc.);
- records management (decentralized files, access, etc.);

— *changes in the organization of the work:*

- define new work positions and their job requirements;
- agree in job posting procedures, so as to avoid repetitive bumping;
- open the new jobs in the new system;

— *elaboration of a program for the sensitization and updating of the expertise of the entire staff:*

- sensitize regarding the service philosophy, the values associated with social integration and the enhancement of the social role of intellectually handicapped people;
- promote the acquisition of appropriate information, skills and attitudes;

— *support of staff working in the community:*

- create and promote procedures for communication between the staff involved;

— *reallocation of material and financial resources:*

- plan the recycling of certain physical resources;
- adapt the budget system to the decentralized management of services in order to better respond to service needs;
- identify the funds that could be part of a budget reallocation;
- identify the organizations and agencies able to contribute financially to the integration of handicapped people into the community;

— *modification of management norms and procedures:*

- supervision of personnel;
- quality control of services;
- management and control of clients' money and personal effects;
- policy on travel expenses, etc.

— *shutdown of internal services no longer necessary:*

- plan the reassignment and retraining of the staff.

Approval of the project

Any project involving the transformation of internal resources into a network of integrated services must clearly outline the entire process to be used by the organization and be authorized by the regional council and the Department before implementation. A response must be forthcoming within a two-month period.

Implementation of the transformation plan

An organization's reintegration plan is rarely implemented globally in a single step. The integration of handicapped people often occurs in successive phases. Certain steps are repeated in each of these implementation phases. Of course, many strategies are possible and the management team must be open to all of them.

However, several elements must be considered when reintegrating a group of handicapped individuals into the community:

1. — ADVISE THE REGIONAL COUNCIL
The institution must advise the regional council, in writing, of the means at its disposal and the intended redistribution of its resources.

2. — REALLOCATE FINANCIAL RESOURCES
The institution must be able to release from its budget the required financial resources or ensure that the necessary authorization has been obtained before initiating the reintegration process. In other words, the management team must reorganize its own services in order to release the required resources.

3. — NEGOTIATE LOCAL ENTENTES WITH THE UNION OR UNIONS IN PLACE

A partnership with the union or unions of the organization is required for harmonious implementation of the transformation process. Under Bill 37, each institution has the right to negotiate local ententes on a certain number of clauses. All administrators must inform and involve the union and the employees in the process of change, if serious problems are to be avoided during the process.

4. — APPLY AN EFFECTIVE TRANSFER STRATEGY WITH REGARD TO CLIENTS AND STAFF

Each time a group of handicapped individuals is reintegrated into the community, employees are transferred from one service to another. It is therefore important to evaluate the necessary human and financial resources, while at the same time respecting the needs of the handicapped individuals and the financial limits of the institution. Every plan must be as cost-effective as possible.

5. — ELABORATE AN INFORMATION STRATEGY

The organization must inform all interested parties. Indeed, all parents and employees must be informed. The methods used to communicate the information may vary from one group to the other; however, information has proven quite effective in reducing anxiety and ensuring the support and collaboration of everyone involved.

6. — SET UP A PROGRAM FOR ORIENTING AND UPDATING THE EXPERTISE OF STAFF INVOLVED

All staff involved must take part in an orientation program to update their knowledge of the philosophy of normalization and of appropriate methods of interaction in an integrated milieu. The training strategy adopted must be based on the particular needs of the integrated milieu, support the parties involved in their new situation, and take into account the costs involved.

7. — CONCLUDE AGREEMENTS WITH CRUCIAL PARTNERS IN THE PROCESS

All adults ready to return to the community are eligible for social assistance, among other things, and must apply at the nearest Centre Travail-Québec office. In order to avoid long delays, the institution may negotiate an agreement with Travail-Québec's regional office, or designate a member to serve as liaison, thereby facilitating this process. It is important that the first steps toward concluding agreements be taken before handicapped people even enter the community; in fact, as soon as their new address is known, so that they may receive social assistance at the right time. In addition, due to the increased number of handicapped people in the current network, agreements should be foreseen with other service organizations, such as adapted transportation services and home assistance services.

8. — CREATE A DECENTRALIZED CONTEXT

In this system of diversified services, certain management procedures and decision-making procedures, must be modified and adjusted, both at the administrative and clinical levels. This new structure demands management "from a distance"; therefore, certain decisions will be made in the field. Certain structures will also have to be modified in order to reflect organizational changes and facilitate service evaluation and follow-up programs in the integrated environment.

9. — PROVIDE A SUPPORT SERVICE FOR THE COMMUNITY

The organization must be present and ready to support parents, residential resources and staff involved in regular programming activities. In addition, it must ensure that intellectually handicapped people receive the services essential for

remaining in the community. General community services must therefore be accessible and available before the handicapped enter the community. If these services are not available, they must be provided by the institution.

10. — REORGANIZE INTERNAL SERVICES
After each group of handicapped individuals leaves the institution, administrators must reorganize their internal services to minimize costs and attain maximum resource efficiency. In so doing they free up additional resources needed for reintegrating the subsequent group of handicapped individuals, or for developing community-based services.

All of these elements could occur in a different order or simultaneously.

Successful social reintegration of intellectually handicapped people requires the collaboration of all partners and a strong sense of purpose.

This approach, centered on the handicapped individual, supposes a major restructuring of the service delivery system. The parties involved must take on new tasks and responsibilities, often requiring considerable human and professional involvement. Administrators and unions have a major responsibility toward their employees and members. They must encourage association with the movement and promote the new service orientations which will ensure a better quality of life for intellectually handicapped people.

PART
6

Social integration: a collective responsibility

The recent actions of the Ministère de la Santé et des Services sociaux reaffirm its determination to achieve the social reintegration of intellectually handicapped people who are presently institutionalized, and to promote the involvement of those already living in the community.

Considerable effort is being made to focus all aspects of the social service network on the individual and on the services he requires. The results of this new orientation will become apparent by an increase in the number of intellectually handicapped people living in the community.

In order to ensure integration, it is imperative that intellectually handicapped people be able to use all public and parapublic services available to the community as a whole. Their participation in the community implies that they have access to various age-appropriate activities throughout life. To achieve this, the organizations in the health and social services network, particularly the reception centres, will have to share the expertise they have acquired through years of working with intellectually handicapped people. In this way, they will be supporting general community services in the crucial period of adaptation.

In the same way, the collaboration of all government departments and organizations providing services, as well as the participation of intellectually handicapped people and their parents, alone or as a group, is essential if intellectually handicapped people are to have an improved quality of life and exercise their rights.

Day care centres and child care services

Child care facilities are an excellent means of integrating pre-school children. Maintaining a greater number of intellectually handicapped children in their home or in a foster family environment will result in a greater demand for regular child care services, whether these be in a day care centre or at home.

Child care facilities will therefore have to make room for these children and adapt their activities and programs to meet their special needs. The "Office des Services de Garde" will also have to ensure that each facility has made the appropriate physical adaptations and possesses the resources necessary to do the job.

Because of their direct involvement with children, child care facilities could take on certain other functions, such as the detection and referral to the appropriate organizations of children who show or risk showing signs of having a handicap. In the case of these children, child care facilities will have to collaborate and become actively involved in the individualized service plan.

Appropriate input from child care facilities can help intellectually handicapped children to pull through certain stages of learning more rapidly, thereby promoting their development and maintainance in the natural environment and integration into a regular school environment.

Educational services

Throughout the course of history, the school system has had to adapt to the changing values of society. It has had to accomodate an increasing number of students and to adapt to their multiple and varied needs.

For example, in order to ensure accessibility to students with learning disabilities, the school system instituted a framework of services which consisted of grouping students with similar difficulties together in the same class. Such classes were often situated in the same school located outside the neighbourhood of most of the students, or even in an institution run by the Minitère de la Santé et des Services sociaux.

This practice seemed acceptable until recently. In the last few years, however, these classes have been questioned by an increasing number of students, parents, professionals and administrators.

The orientations supported in this document will result in severely handicapped children being kept at home with their family or in a similar substitute environment, instead of being grouped in large numbers in a residential facility. Thus, the demand for education will be more and more on a local and individualized basis.

Consequently, over the next few years, school boards will have to adapt their services in order to ensure access to educational services for all intellectually handicapped individuals of school age and to promote their access to neighbourhood schools, and preferably to regular classes within these schools. Today, even if compulsory schooling exists for all children, access to schooling is not a reality for many intellectually handicapped children.

Integration into the school system therefore demands providing the means toward this end, such as providing support services to the student and teacher in regular classes. Adult education services will also have to adapt programs in order to meet the special needs of handicapped adults.

Access to the workforce

Intellectually handicapped people encounter major difficuties in their quest to integrate the job market, and the large majority of them are subsequently unemployed. Because our society places a great deal of importance on work and the economic independence that comes with it, many intellectually handicapped people wish to be self-reliant and contribute to the economic life of the province.

The orientation currently being promoted and the effort put into preparing intellectually handicapped people for the workforce lead one to predict that in the future a greater number of intellectually handicapped people will be able to satisfy employer demands and penetrate the job market on their own.

In order to promote integration into the work community, the various economy oriented government departments and providers of general and specialized services must innovate and join forces.

Firstly, schools, by promoting the integration of handicapped students and developing professional training programs, will be giving these students an opportunity to adapt to a social environment, widen their sphere of activity, and acquire the necessary education and training to penetrate the job market. Secondly, employment support programs, such as those offered by manpower centres and the Office des Personnes Handicapées du Québec, aimed at compensating a genuine loss or loss of income incurred by the employer during the training and orientation period, will have to satisfy an increased demand and continue to adapt to the needs of handicapped people.

Steps must also be undertaken to de-mystify intellectually handicapped people in the eyes of employers through appropriate sensitization. Employers could be encouraged to adapt recruiting and selection procedures to promote the hiring of intellectually handicapped people in their companies.

Municipal services

The fact that a greater number of intellectually handicapped individuals is socially integrated also means that a greater number of them will request services that must be set up by municipalities: namely, accessibility to public places, recreational services and adapted transportation services.

Considering that many people have motor deficiencies, accessibility to municipal public facilities constitutes a first and primary expectation. These people will also want to have access to recreational services available to the general public. Existing services will have to be adapted to meet their needs and expectations. Or new ones will have to be created.

Finally, many intellectually handicapped people will have to travel and use public transportation services. The social service network, in collaboration with the municipalities, will therefore have to prepare these people and promote their use of the regular transportation system. For many intellectually handicapped people, adapted transportation services will be their only means of getting around. It is therefore important that adapted transportation services be available in all regions of the province.

When a large number of individuals with similar or diverse problems are grouped together, acceptance by those around them and social integration are needlessly compromised. The health and social services network, together with the municipalities, must ensure that the residences connected with the public service organizations are evenly distributed throughout the community.

It is important that elected municipal representatives and municipal governments actively respect this orientation, whether it be in the speeches made to their constituents or at the legislative or administrative levels. Being close to the community, they are sensitive to the concerns of their constituents, and can therefore influence their comprehension and attitudes toward intellectually handicapped people. In this respect, municipal elected representatives and administrators play a very important role in making change happen.

Office des Personnes Handicapées du Québec

A Bill Promoting the exercise of the rights of intellectually handicapped people confers on the Office des Personnes Handicapées du Québec the responsibility for the coordination of government departments, municipalities and school commissions and other public or private organizations that offer services to these people. This coordination is in the areas of access to housing and other services, travel, integration into the work community, access to educational services, and participation in socio-cultural and leisure activities in the community.

Upon the request of the intellectually handicapped individual, the Office may also act on his behalf and help him to approach these various organizations.

From time to time, the Office des Personnes Handicapées du Québec will become involved in the social integration of a specific handicapped person by providing pertinent information and guidance, and by promoting his interests through whatever means possible.

In the same way, under the provisions of the Bill, the heads of regional and interdepartmental coordination at the Office will often be asked to participate in promoting the integration of a handicapped person into school and certain professional and social milieux.

Clients and their parents

Traditionally, when a handicapped individual, especially a child, was institutionalized, the government was considered a parental substitute who assumed responsibility for the person. In such a context, parental involvement was often limited, even nonexistent.

However, over the last several years, the number of parents who no longer wish to relinquish their responsibility toward their child has steadily increased, even in cases where the child resides outside the family home.

They wish to be more involved and have their parental role and responsibilities more recognized, with appropriate support from the public service network. More and more parents prefer to keep their child at home in order to ensure maximum development, but with the assurance that the child has access, like any other person, to community life and to services available to the community as a whole. In order to help their child and obtain the support they need, they ask that specialized services and structures for the evaluation and coordination of services be put into place.

Moreover, it was the efforts of parents and their associations that prompted the Ministère de la Santé et des Services sociaux and its service network to undertake and pursue the transformation of current institutional resources into a network of integrated community-based services in order to promote the maintenance or the return of the handicapped individual to a normal setting. However, this objective will fail without the involvement of handicapped persons and their parents on an individual basis or as an association of concerned citizens.

Today there is greater awareness of the important role parents can play in the development and education of their child. In fact, they become valuable participants when they have the necessary support and when they are listened to.

The social reintegration of handicapped individuals does not, however, mean the return of the currently institutionalized individual, especially in the case of an adult, to his natural family. No parent shall ever have to take back a child if he does not so desire. In such a case, other resources will be put at the disposal of the person so that his needs may be met to the greatest extent possible.

Involvement of the handicapped person and his parents is considered essential to a proper evaluation of his needs and to the elaboration of his individualized service plan. In addition, parents must have the opportunity to become involved in the management of services both at the local level through the clients' committee and the boards of directors of the public service organizations, and at the regional level through administrative committees and other existing groups.

Parent and client groups and associations

Associations of parents and clients are a major force in the social integration of intellectually handicapped people. Their actions are focussed on the needs of the family, the defense of the rights of the handicapped, and collaboration with providers of specialized services.

These associations have, in fact, chosen to play a leadership role in their community, serve as a source of reference and support, share information and expertise, demand adequate fulfillment of the real needs of handicapped people, and monitor the quality of services. They represent several very important resources for handicapped people and their families, such as the support-parents program, the family assistance service, citizen advocacy, the Mouvement des Personnes d'abord, etc.

The involvement of these associations will always be essential in order to provide information, support and publicity to parents, professionals, administrators, as well as to other members of the community. They play an essential role in the implementation of social reintegration projects and in the redistribution of services because they promote the rights and interests of all handicapped individuals.

PART
7

Proposals for action

As noted earlier, over the next ten years, the real challenge for the people of Quebec with regard to intellectually handicapped people is to provide the means by which handicapped people can enjoy a quality of life similar to that of other citizens.

Significant differences exist between the life lead by the majority of the population and by intellectually handicapped people. Services presently available to handicapped people do not necessarily correspond to what they require, nor to the values and principles advocated in this document. The solution is to put into place a range of services and programs which will promote skill development for handicapped people and their integration into the community.

These measures must also modify the negative perception of handicapped people by the public and reverse the long-standing practice of institutionalization, which is clearly no longer justified. And they must also lead to the evolution of a collective consensus which is respectful of intellectually handicapped people.

In order to achieve successful social integration of handicapped people the Department and its social service network must establish clear-cut objectives and specify the measures required to reach these objectives. The objectives to be attained are as follows:

- gradually put an end to the institutionalization of intellectually handicapped people for the sole reason that they are handicapped;
- build and promote a comprehensive range of specialized services essential to intellectually handicapped people and their families in each region and subregion of the province over the next five years;
- promote access by intellectually handicapped people to general community services available to the population at large;
- improve the quality of services offered to handicapped people and their families;
- promote the involvement and participation of parents;
- increase community participation in helping to socially integrate intellectually handicapped people.

Put a gradual end to the institutionalization of people solely on the basis of an intellectual handicap

In light of the importance of social integration, establishments must limit the number of admissions to institutions and promote the social reintegration of those who have been institutionalized, whether they have other related handicaps or not, and as long as neither their health nor safety is at serious risk in the process.

In line with this objective:

- as of 1989, demands for residential services for children will be channelled into a network of community-based services;
- as of 1989, handicapped people will no longer be admitted to chronic long-term hospitals or to custodial care reception centres;
- before 1991, demands for residential services for adults will have been channelled into a network of community-based services;
- over the next five years, the successful reintegration of 50% of all intellectually handicapped adults currently institutionalized.

In light of the importance of an integrated milieu for the development of children, organizations should give priority to children in the reorganizational plans.

Each region must develop a comprehensive range of specialized community-based services for handicapped people and their families. The Department will have to ensure that regions put structures into place that will avoid the "revolving door syndrome", that is to say the readmission of handicapped people in custodial care centres, reception centres or in chronic care hospitals.

To ensure that these objectives are reached, the Department will have to develop concurrently a program to sensitize workers and professionals from social and medical services regarding their specific roles in detection, prevention and research. It will also ensure that parents have access to information concerning specialized services and overall support available to them from the social service network.

Provide a comprehensive range of specialized services for intellectually handicapped people and their families in each region and subregion over the next five years

As mentioned previously, the achievement of this objective is crucial to the social integration and reintegration of intellectually handicapped people. This range of services includes all of the previously mentioned specialized services. However, priority should be given to certain specific services:

- availability and accessibility of infant stimulation and home-oriented training assistance services for all pre-school age children as of 1990;
- availability and acccessibility of respite care for the majority of the families of children by 1990 and of adults by 1992;
- availability and accessibility of work training and support services for all adults presently living in the community by 1993;
- implementation in each region of structures for access to services and of systems for the elaboration, orientation and revision of individualized service plans in 1989.

The transformation of hospital and reception centre institutional services into a network of quality, specialized, community-based services requires detailed planning at the regional and subregional levels. This planning must be done by and with all the partners in the social service network and it must be completed before the implementation stage.

Each regional council will have put together a plan for the regional organization of services by 1989, and each social service agency shall submit a project for the transformation of its services within the context of this regional plan.

The regional councils and the social service organizations will receive the following help in their work from:

A GROUP OF EXPERIENCED RESOURCE PEOPLE:

Experienced resource people from the social service network will help administrators in the preparation, implementation and evaluation of their projects.

APPROPRIATE TRAINING PROGRAMS:

The Department shall ensure the availability of training and orientation programs for administrators in order to facilitate the transformation process. Recommendations for recycling and retraining programs for direct care staff could also be made in order to facilitate their adaptation to new work demands, thereby ensuring a higher quality of service after the transformation process.

FINANCIAL AID:

Even though most organizations already have the financial resources required for the transformation process, the Department recognizes that some "one-shot" financial assistance might be needed to get through certain stages of the plan. Therefore, it will put procedures into place to provide financial assistance to projects that come from

the organizations. Development budgets could be made available to regions with less than the minimum level of community-based services if resources are not available in other service networks in the region. However, all development budgets will be oriented toward the establishment of community-based services.

In order to implement this new service orientation, the Department will develop prototypes of developmental programs to fulfill the particular and specific needs of handicapped people and their families.

Promote access to services generally available to the population at large by intellectually handicapped people

The process of social integration implies that handicapped people have access to the same services as everyone else.

It should follow from this objective that:

- appropriate government departments and public service organizations develop services with a view to promoting the social integration of handicapped people.
- access to these adapted services on the part of handicapped people will enable the Ministère de la Santé et des Services sociaux to abandon those services that do not come under its normal responsibility.

The Department will work with other departments providing public services by informing them of the needs of handicapped people and by giving them the support needed in order to make their services accessible.

In view of its mandate, the Office des Personnes Handicapées du Québec should have an advisory and a leadership role in promoting the collaboration of the various departments and service organizations involved in this process.

Improve the quality of service offered to intellectually handicapped people and their families

It is important for the Ministère de la Santé et des Services sociaux that the range of services set up in each subregion of the province be a network of services of high quality that respect the philosophy and the orientations advocated above. The Department expects that:

- the social service network will offer an acceptable range of services and an acceptable level of support and assistance;
- the services offered will be of superior quality corresponding to the values, orientations and policies advocated throughout this document;
- the results obtained in the service system will correspond to the results expected by those involved in the process;
- the individuals who are under social protection or who are severely handicapped will receive services enabling them to live in the community;
- the quantity of services will correspond positively to the resources invested in that service system.

In order that these changes be known and recognized at the provincial level, the Department, in collaboration with the proper authorities at the regional level, will develop structures and systems for the evaluation of service quality and overall network operation as well as evaluation procedures with regard to the social reintegration of intellectually handicapped people and the transformation of resources in the social service network.

Promote the involvement and participation of parents

The participation and involvement of parents in all aspects of the lives of their children must be promoted and encouraged. In fact, they must be active participants in decisions affecting their child.

In the next few years, a special concerted effort must be made by the public service organizations and the regional councils to promote the involvement of parents in their activities. Greater parental involvement with decision-making groups and in consultation forums, such as administrative committees, clients' committees, parents' associations and advocacy groups, is absolutely essential. Better communication must also be ensured between parents and professionals and direct care staff.

The Ministère de la Santé et des Services sociaux:

- shall ensure that parents and all future parents receive the information vital to the fulfillment of their role as parents of handicapped people;
- shall release financial resources in order to contribute specific financial aid toward sensitizing, informing and training handicapped people and their parents in this area.

Increase community participation in helping to socially integrate intellectually handicapped people.

The community must participate in these efforts guided by a spirit of collective responsibility. A favourable attitude on the part of the population represents a major asset for the social integration of intellectually handicapped people.

Our efforts are aimed at developing:

- a better understanding of the handicapping condition;
- positive attitudes toward intellectually handicapped people;
- a desire to take on this collective responsibility;
- interpersonal skills essential for increased interaction between handicapped and non-handicapped people.

In order to reach this goal, certain measures will be taken by the public service network, regional councils and the Ministère de la Santé et des Services sociaux. A group-by-group approach should be promoted.

Proposed measures are as follows:

- a campaign to sensitize the general population and various target groups;
- regional information campaigns;
- promotion by the public service organizations of their community-based services;
- that the Department and the Office des Personnes Handicapées du Québec pressure other Departments (Education, Higher Education and Science, Municipal Affairs, etc.) to obtain their collaboration in order to have a fair distribution of services necessary to promote the integration of handicapped people.

In summary, these objectives and propositions constitute an essential foundation; however, the challenge does not end here. With a clear knowledge of the objective to be attained, namely the integration of intellectually handicapped people, all interested parties within their own sphere of activity will have to put into place their own programs in order to breathe life into this collective project.

Conclusion

Society is becoming more and more receptive to the idea of integrating intellectually handicapped people into the community. It is now accepted that handicapped people live in their natural milieu, enjoy living conditions similar to those enjoyed by others and have access to the same community services. The home environment offers a far better guarantee of a life of quality and is more conducive to the adaptation of the handicapped person to his community. Various experiences, here as well as in many other countries, have shown that it is possible to promote the social integration of intellectually handicapped people on a large scale.

Well aware of its responsibility regarding the fate of many intellectually handicapped people and of the help it can offer them, the Ministère de la Santé et des Services sociaux urges its partners to make room for these people. This challenge relies on everyone for success.

In this respect, this document should help all interested parties achieve the integration of all intellectually handicapped people. Planning documents at the regional and provincial levels are the next step. These will appeal to all partners in the public social service network for flexibility on their part in adapting their services to meet the needs of handicapped persons and their families. Other Departments and other organizations will also be challenged to bend and shape their practices and services in order to serve handicapped people and to promote a higher quality of life for them.

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